



### Attitudes to Dementia

# Maria McManus & Paula Devine 18 October 2011







- UK
  - 2011 750,000
  - 2021 > 1 million

Alz. Research Trust (2010)

- Northern Ireland
  - 2011 19,000 people
  - 2051 60,000 people
    - DHSSPSNI (2010)

- Globally
  - 36 Million
  - Doubling every 20 years...
  - 66 million by 2030
    - ADI

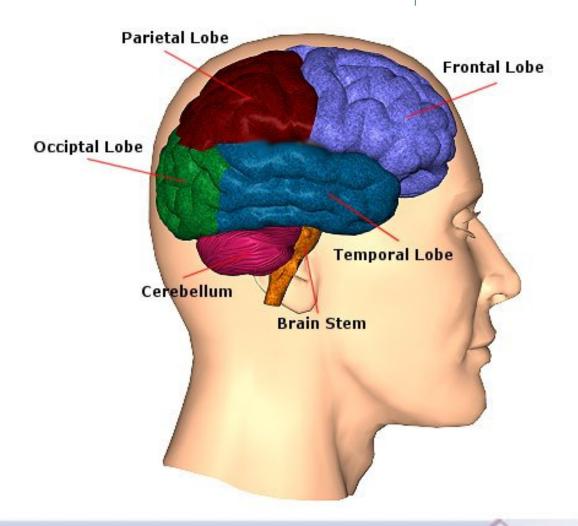








### The brain







## **Types of Dementia**





## Disabilities of dementia usually include

- Impaired memory, especially recent memory
- Impaired learning
- Impaired reasoning
- High levels of stress
- Difficulty adjusting to the sensory/mobility impairment of normal ageing





"the disabilities that people experience are a result of the relationship between what's happening in the brain and their social and built environment."





## Understanding the Experience of the Person with Dementia

'The experience of dementia is characterised by both the experience of loss (of social roles and relationships as well as of neurological functioning) and the threat of further losses to come and result in a range of emotions including grief, depression, anxiety, despair and terror. The experience of dementia therefore represents a profound threat to the individual's identity- to their sense of who they are'





## **Impact of Dementias**

- Deterioration in cognition
- Loss of socialisation
- Decreased interaction
- Depression
- Increased alienation
- Increased isolation
- Increased agitation





## **About the survey**

- 2010 Northern Ireland Life and Times Survey
- 1205 respondents aged 18 or over, living across Northern Ireland
- Module exploring knowledge and attitudes in relation to dementia
- Module funded by The Atlantic Philanthropies





# Do you know anybody personally who has dementia?

- 45% of respondents knew someone who had dementia, mostly family members
- Knowledge of someone with dementia varied by age:
  - Approximately one quarter of those aged under 35 knew someone with dementia
  - Approximately one half of those aged 35 or over know someone with dementia





## UNIVERSITY OF STIRLING

Knowledge of Dementia	% saying 'True'
Dementia is a disease of the brain	94
Dementia is a mental illness	54
Dementia is part of the normal process of ageing	28
Dementia is another term for Alzheimer's disease	58
People who eat healthily and exercise are less likely to get dementia	29
There are drug treatments that help with dementia	75
There are many different kinds of dementia	72
Dementia can be cured	6

Describing Dementia	%
Confused	90
Frightened	62
Lost	58
Unpredictable	52
Trapped	44
Sad	38
Angry	36
Dangerous	16
Pathetic	16
Нарру	7
Gentle	6
Kind	4
Fun	3
None of these	<1
Other answer	1

Y/

Living with Dementia	% agree or strongly agree
There comes a time when all you can do for someone with dementia is to keep them clean, healthy and safe	83
Other people take over making decisions for people with dementia far too much	48
Once they have dementia the person you knew eventually disappears	75
As soon as someone is diagnosed with dementia they are not treated like a thinking human being anymore	46
For people with really bad dementia I don't think life is worth living	27
People with dementia are like children and need cared for as you would a child	73
People with dementia should be involved in activities in the community	87
It is better for people with dementia and their families if they are cared for in a residential unit or a nursing home	34
There is little or no benefit to be gained from telling someone they have dementia	36
People who have just been diagnosed with dementia are unable to make decisions about their own care	29
There is no point talking to someone with dementia, as they won't be able to understand	14

	%						
	Live alone	Manage medication	Drive	Electronic tag			
Just diagnosed							
Definitely/ probably	19	12	4	64			
It depends	35	24	15	20			
Probably/ definitely not	39	62	80	15			
Diagnosed a long time							
Definitely/ probably	3	2	1	69			
It depends	16	11	6	15			
Probably/ definitely not	81	87	93	16			







## Conclusions

- Attitudes
  - Public policies
  - Care and services
  - Public awareness
  - Support and information for people with dementia and their carers







## Good news

- 94% of respondents know dementia is a progressive brain disease
- 87% think people with dementia should be involved in activities in the community







## Must do better.....

- STIGMA
- Access to care
- False belief 'nothing can be done'
- Emerging from the shadows
- Shine a light





## Must do better.....

- Improve information for carers of people with dementia
- Do raise expectations

Paternalistic views







## Must do better.....

- Modifiable risk factors
- Good diet
- Meaningful activities
- Social networks
- Modest alcohol intake
- EXERCISE!!!!!







## Must DO!!!!

- Diagnose early
- Inform people with dementia
- Listen to people with dementia
- Learn from people with dementia







#### **Attitudes to Dementia**

The success of our job should be governed by enhanced quality of life for people with dementia

